



MEDIA KIT

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WHAT IS PWS?



Insatiable Hunger

Individuals with PWS experience an insatiable hunger, which can lead to overeating and obesity.



Behavioral Issues

PWS is often associated with temper outbursts, obsessive-compulsive tendencies, and anxiety.



Low Muscle Tone

Infants with PWS often have low muscle tone, causing feeding difficulties and delayed milestones.

[LEARN MORE](#)

WHO WE ARE

OUR HISTORY

The Prader-Willi Syndrome Association | USA (PWSA | USA) is a national nonprofit organization dedicated to supporting individuals and families affected by Prader-Willi syndrome (PWS), a rare genetic disorder. Since our founding in 1975, we have become the leading voice for PWS awareness, support, education, and advocacy across the United States.

OUR MISSION

Our mission is to enhance the quality of life for those affected by PWS through support, research, and advocacy. We provide essential resources, raise awareness, and fund research initiatives aimed at understanding PWS and improving treatment options.

[LEARN MORE](#)


Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES





WHAT WE DO

FAMILY SUPPORT

We offer compassionate guidance to families navigating the challenges of living with PWS. Our support includes connecting families with medical professionals, resources, and peer networks to help them manage daily care.

ADVOCACY & AWARENESS

PWSA | USA actively advocates for policies that improve the lives of individuals with PWS. We work closely with lawmakers, healthcare professionals, and the general public to raise awareness and understanding of PWS.

EDUCATION & RESOURCES

We provide a wide range of educational materials, workshops, and training to equip caregivers, educators, and medical professionals with the knowledge needed to support those affected by PWS.

RESEARCH & INNOVATION

We are committed to advancing research on Prader-Willi syndrome. Through funding research initiatives and supporting clinical trials, we strive to move closer to effective treatments.



OUR TEAM & LEADERSHIP



Stacy Ward, MS, BCBA
PWSA | USA CEO



Marguerite Rupnow, MBA
Board of Directors, Chair



Tina Ihlenfeld, MBA
Board of Directors, Treasurer



Denise Servais
Board of Directors, Secretary

[READ CEO BIO](#)[READ BOARD MEMBER BIOS](#)[READ STAFF BIOS](#)

PWSA | USA STAFF

Listed in alphabetical order

Charles Conway, Jr., Executive Administrative Assistant
Angela Frazier, Events Coordinator
Anne Fricke, Marketing & Communications Coordinator
Lynn Garrick, MSN, RN, Medical/Research Coordinator
Andrea Hughes, Database Coordinator
Carrie Ilijevich, Director of Marketing & Communications
Sarah Kasaby, Information & Referral Specialist
Dorothea Lantz, Director of Community Engagement
Amy Maust, CPA, Director of Accounting

Katie Martinez, Fundraising Coach: Team & Online Events
Melanie Zalman, Director of Development
Kristi Rickenbach, Parent Support Coordinator
Kristen Starkey, Accounting Clerk
Elaine Towle, Advocacy Specialist
Kim Tula, MS, CSW, Senior Family Support Counselor and Trainer
Stacy Ward, MS, BCBA, CEO

PWSA | USA BOARD OF DIRECTORS

Listed in alphabetical order

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Dini Rao
Marguerite Rupnow, MBA, Chair

Ann Scheimann, MD
Denise Servais, Secretary
Michelle Torbert

STORIES OF PWS

Click on the images to read/watch these inspiring stories



VICTORIA



KHALED



ANDREA



JACOB



MIRA



BOOTHIE



Our **Spotlight on PWS** series strives to share the everyday moments of our loved ones with PWS - we want to know more about individuals with PWS, celebrate with them, share in the frustrations, and provide support when and where we can. The experiences shared here can help others learn how to meet similar challenges with more preparation or might inspire others to see their goals through. Click the button below to read these stories.

[READ MORE SPOTLIGHT ON PWS STORIES](#)



MARKETING ANALYTICS

FOLLOWERS

	16,088
	2,763
	1,519
	2,483
	1,179

PWSAUSA.ORG

Avg. Monthly Visitors	23,781
Avg. Monthly Page Views	48,893
Avg. Engagement Time	1:43

BLOG

Avg. New Monthly Posts	14
Avg. Monthly Post Views	3,161
Avg. Monthly Readers	275

PODCAST LISTENERS

New episode shared across all Podcast streaming platforms every Tuesday

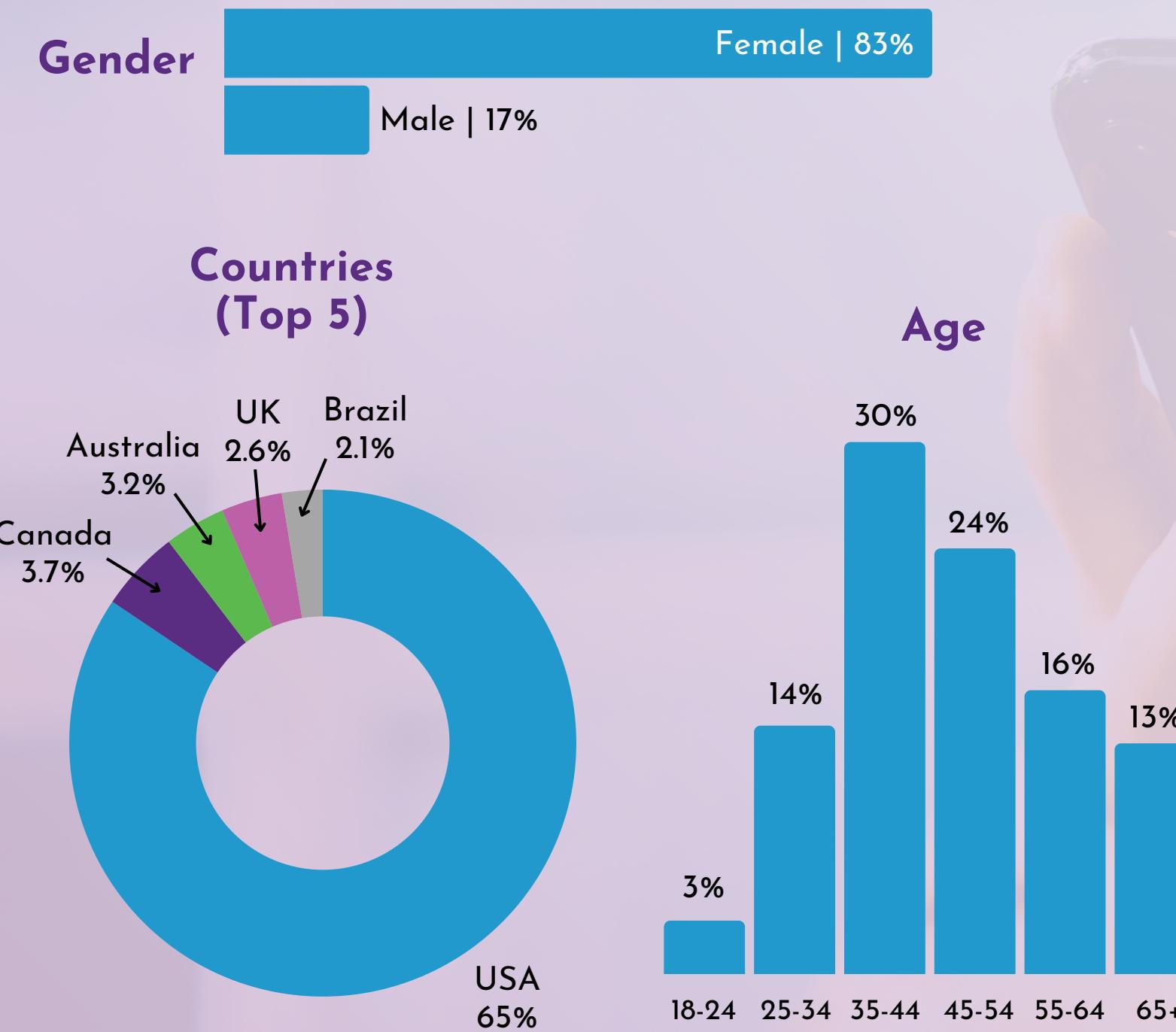
10,528 Total Episode Downloads
462 downloads on top episode
On average, 180 listens per episode

PWS United Podcast launched in August 2024

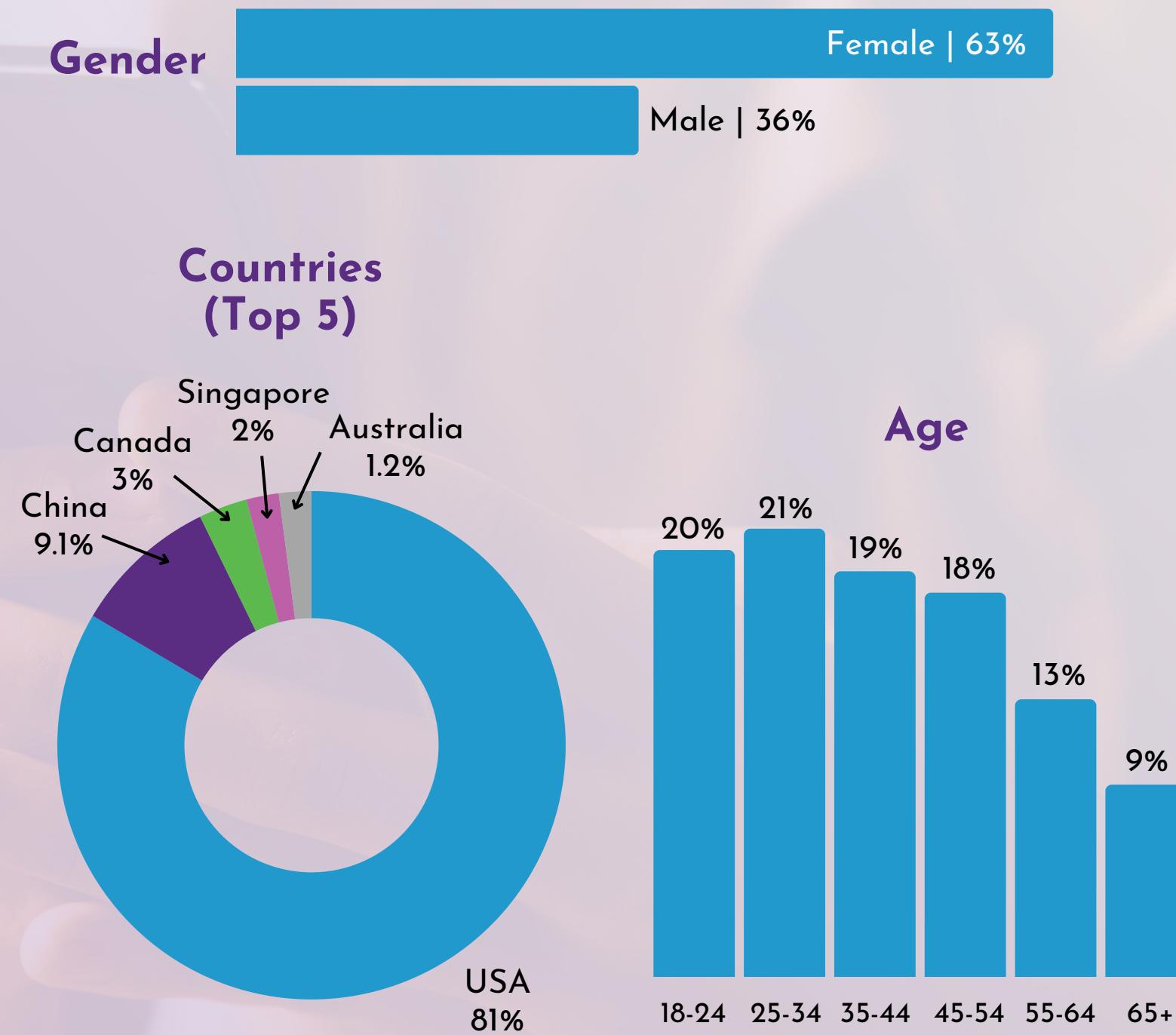


MARKETING ANALYTICS - DEMOGRAPHICS

SOCIAL MEDIA FOLLOWERS



WEBSITE VISITORS





SUB-BRANDS OF PWSA | USA



PWSA | USA's Podcast

[LEARN MORE](#)



BUILDING **BRIGHT** FUTURES FOR PWS FAMILIES

Peer-to-Peer Fundraising

[LEARN MORE](#)



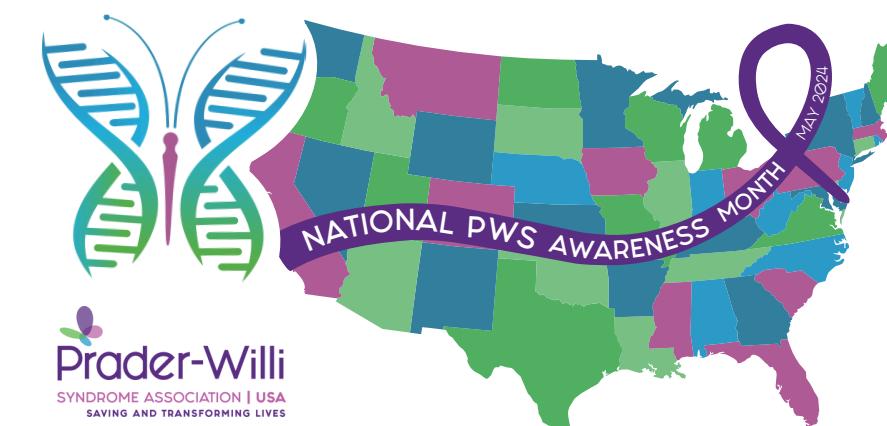
Advocacy Efforts

[LEARN MORE](#)



Annual Fundraising Drive

[LEARN MORE](#)



PWS Awareness Month (May)

[LEARN MORE](#)



ECHO 4 PWS: Healthcare Provider Series

[LEARN MORE](#)

PWSA | USA EVENTS



PWSA | USA 2027
NATIONAL CONVENTION

Biennial Conference

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D.C. Fly-In

[LEARN MORE](#)



Moms' Retreat

[LEARN MORE](#)



Residential Providers Conference

[LEARN MORE](#)



50th Celebration: Journey of
Hope Gala

[LEARN MORE](#)



2026 EDITORIAL CALENDAR

EMAIL, SOCIAL MEDIA, PODCAST, BLOG SCHEDULE

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
PWS Hope United fundraiser/event social media post	Monthly focus community prompt social media post	PWS United Podcast episode release Standalone emails sent (event, campaign, program focuses)	Ask Nurse Lynn question/answer blog article	Resource spotlight social media post New Family Support blog article Community-contributed blog article (first Friday of every month)	PWSA USA Pulse Newsletter (emailed bi-weekly) Spotlight on PWS social media post	

PWSA | USA's 2026 editorial calendar is packed with exciting content designed to inform, inspire, and unite the Prader-Willi syndrome community. From social media campaigns and podcast episodes to email updates and blog articles, we're committed to sharing stories, programs, and resources that make a difference.

If you have a program, service, or information you'd like us to help spread the word about, we'd love to collaborate! Reach out to our communications team at communications@pwsausa.org to discuss how we can amplify your message through PWSA | USA's platforms. Let's work together to create greater awareness and support for the PWS community in 2026!

EVENTS, FOCUSES, CAMPAIGNS BY MONTH

JANUARY	FEBRUARY	MARCH	APRIL
PWSA USA Staff Retreat (Jan. 22-25) Mental Wellness Month	National Caregivers Day (Feb. 20) Rare Disease Week on Capitol Hill (Feb. 24-26 Washington, D.C.) Rare Disease Day (Feb. 28)	Developmental Disabilities Awareness Month National Nutrition Month Sleep Awareness Week (March 8-14) Neurodiversity Celebration Week (March 17-23) Clint Hurdle Hot Stove Dinner (March 21 Bradenton, FL)	National Occupational Therapy Month National Siblings Day (April 10) National Volunteer Week (April 19-25) Solidarity & Spice: Rasika Wine Dinner PWS (April 25 Washington, D.C.)
MAY	JUNE	JULY	AUGUST
Prader-Willi Syndrome Awareness Month PWSA USA's D.C. Fly-In (May 4-6 Washington, D.C.) PWSA USA's United We Brunch Campaign National Nurses & Teacher Appreciation Weeks (May 6-12)	Scoliosis Awareness Month	National Minority Mental Health Month	Gastroparesis Awareness Month National Make-a-Wish Month PWSA USA's Residential Providers Conference (Aug. 21-22 Savannah, GA) PWS United Podcast Anniversary (Aug. 31)
SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER
Newborn Screening Awareness Month National Service Dog Month Direct Support Professionals Week (September 6-12) World Physical Therapy Day (Sept. 8) World Narcolepsy Day (Sept. 22) Prader Silly: A Night of Rare Laughs (Sept. 30 Nashville, TN)	National Physical Therapy Month 16th Annual Hunter Lens Golf Tournament (Lakeville, MA) World Mental Health Day (Oct. 10) PWSA USA's Moms' Retreat (Oct. 16-17 Park City, UT)	PWSA USA's Angel Drive Campaign National Family Caregivers Month International 15Q Day (Nov. 15) World Prematurity Day (Nov. 17)	PWSA USA's Angel Drive Campaign Giving Tuesday (Dec. 1) International Day of Persons with Disabilities (Dec. 3)



LEARN MORE ABOUT OUR WORK

At PWSA | USA, we're here to support, collaborate, and share the stories that matter most to the Prader-Willi syndrome community. Whether you're seeking information, want to help spread awareness, or explore partnership opportunities, we'd love to hear from you. No request is too small - reach out today and let's make a difference together. For media inquiries, please email communications@pwsausa.org or call (941) 312-0400.



(941) 312-0400



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